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Submission to the Productivity Commission Disability Care & Support

There are four primary areas of my concern, which are in priority order:

1. Need for sufficient properly funded services enabling early support for people with mental illnesses.

Large numbers of people with mental health problems are now in prison rather than receiving the initial support they need, which could improve their lives and mean they never come within correctional service systems.

I would like to draw your attention to the recent ABC Radio Background Briefing Program, which illustrates some issues:

“Low IQ and in jail: Many intellectually disabled people end up in jail. They plead guilty to minor crimes not understanding either social rules or the consequences. Hear the story of Melissa who has an IQ of 57, which is in the lowest 1%, and who still faces jail.”

<http://www.abc.net.au/rn/backgroundbriefing/stories/2011/3191335.htm>

I think establishing special courts is far from the best approach, much earlier intervention is essential. The question is how can all of our representative governments and we decently support people with intellectual disabilities and those responsible for their care? Funding correctional services needs to be a last resort. The wasteful correction service funding needs to be diverted to the National Disability Insurance Scheme.

2. Essential Care throughout life

The above groups of people are part of a larger subset of people with disability of any kind who need substantial care throughout life. I am impressed with the large numbers of parents of children of all ages including adult children pleading for accommodation and care for them. The new systems must deal properly and decently with all of them to give peace of mind for all so as parents age everyone is assured that children will be properly cared for after they die.

3. Increase in proportional workplace participation in government jobs.

Employment of people with disabilities by governments has dropped proportionately in recent years. I would like to see mandatory benchmarking with target numbers of people with disabilities to be employed introduced or reintroduced at all three levels of government particularly local government.

In addition, the new authority needs the power to audit and report to federal parliament on examples of best practice performance. Such a measure and added incentives might encourage government to be a model employer and influence the private sector likewise. Employment of people with disabilities

would give them more say, normal economic involvement, and their presence would facilitate increasing physical and behavioural change in access to jobs and buildings. It is easy not to make workplaces accessible if the need is purely speculative. Adapting workplaces benefits not just the incumbent but also those who may follow.

4. Social Inclusion – include in recommendation for Public Reporting

Governments particularly local government can play a much larger role in facilitating inclusion of all people with a disability within their jurisdictions as of right. I believe this could substantially decrease their need for services. Everyone including taxpayers would benefit.

Accessibility contributes to social inclusion and has two aspects: attitudinal and physical. There is fear of disability, which leads to us developing an attitude that we would rather not deal with it. There is also the extra care needed to improve physical design for accessibility.

An example is accessibility to community transport and shopping. Ability to shop for essentials is important for independence. Yet the trend is away from corner shops that people can live close to. Instead, essentials must be obtained from supermarkets in large shopping centres. These are deliberately designed so people have to move past large numbers of speciality shops to reach the supermarkets. In addition, car parks in the latest centres are inaccessible for community transport.

Strong regulation is necessary and totally absent from current local government planning rules and Development Control Plans (DCPs). Increasing land values have resulted in below ground rather than above ground car parks with minimal ceiling heights making access for community transport and emergency vehicles impossible.

I welcome the statement on page 4.24 about improving access to mainstream services:

“The Commission considers that the NDIS should also have a public reporting role. This would involve reporting annually on the progress made by governments, in the areas of education, housing and transport, to improve services to people with disability. In doing so, the scheme could draw attention to both good and bad examples.”

NDIS = National Disability Insurance Scheme

Please make public reporting a priority recommendation and add social inclusion. It is an effective mechanism for encouraging governments to promote social inclusion in this case by design. The change in design and planning required in this example would be to local government DCPs and Access to Premises Standards federally.

Requirements for such shopping centres could be undercover access from public transport and community buses. Accessible standing areas for buses and covered accessible waiting/boarding areas within say 100 metres of the major supermarkets selling essentials could be required. At present developers can build shopping centres to the minimum requirements and claim hardship if people complain to the Australian Human Relations Commission after construction.

Other examples would be through improved accessibility of public open spaces and buildings and social /public activities, provision of home modification and maintenance services and volunteering activities, which are the responsibility of governments.

Governments can act as an example. Then we can expect and require the private sector to improve. Governments can make substantial improvements to the quality of life of people with disabilities through social inclusion particularly by acting locally. Promoting the independence of people with a disability is the most cost effective way of limiting the vast need for support services and related funding.

6. Draft Recommendation 4.4 – unwanted consequences?

DRAFT RECOMMENDATION 4.4

People should pay the full costs of services (primarily therapies) for which clinical evidence of benefits are insufficient or inconclusive if they wish to consume those services.

As it stands this recommendation will enable the Government and NDIS to deny a real benefit to some people with a disability, that of controlling their therapy. While service providers may be funded to innovate, the equivalent ability may be denied to those with a disability. The power to cash in and self direct funds to alternative therapies may thus be denied.

Elsewhere the Draft Report states that data on effectiveness is poor. As the draft recommendation stands those with a stake in the mainstream therapies will thus decide effectiveness on poor information. It is important that a limited number of people try alternatives, as this is the way effective innovations become recognised and accepted.

When conventional methods do not work people want to try alternatives. They often cannot fund such therapies themselves. Enabling a small number of people who do not benefit from any mainstream therapy or method to have alternative therapies serves everyone. How else will new therapies that work better become recognised as effective? People need to be enabled to try new methods. In the longer term, such a measure would limit costs. How to determine where the margin lies is difficult. On what authority the NDIS would make decisions is a matter for further investigation and implementation. This difficulty is not a sufficient reason to make such funding impossible.

People with different ethnic and Indigenous backgrounds particularly those with a mental disability may wish to have therapies unrecognised by mainstream Australia. There should not be a deterministic attitude by the NDIS in such matters but reasonable response to advice.

An example outside the field of disability is the treatment of stomach ulcers. Many claims were made and for many years ineffective treatments funded. Therapists based all these treatments on false premises. Yet when researchers discovered that pathogens cause the ulcers, there was a great deal of resistance from stakeholders in maintaining their ineffective treatment until the final recognition of the new treatment. Today's conventional wisdom becomes yesterdays discarded nonsense. Progress depends on accepting this truth.

It is important to avoid other unwanted consequences of recommendations. For example, the proposed ability to employ staff as attendant carers gives a valuable new freedom to more people with a disability than currently. However, what happens if a carer moving a person with a disability causes him or her injury? If the carer is employed by an agency, the agency is liable and can cover the risk through professional indemnity/public liability insurance. However, experience is that insurers will not cover this risk when the person with a disability is the employer as their disability/injury is considered to be a pre-existing condition. The effect is to move the cost from agencies to people with a disability employing carers. Could the NDIS then become the insurer and self-directed care packages include funds so people with a disability could use some of their package to insure against this risk?

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